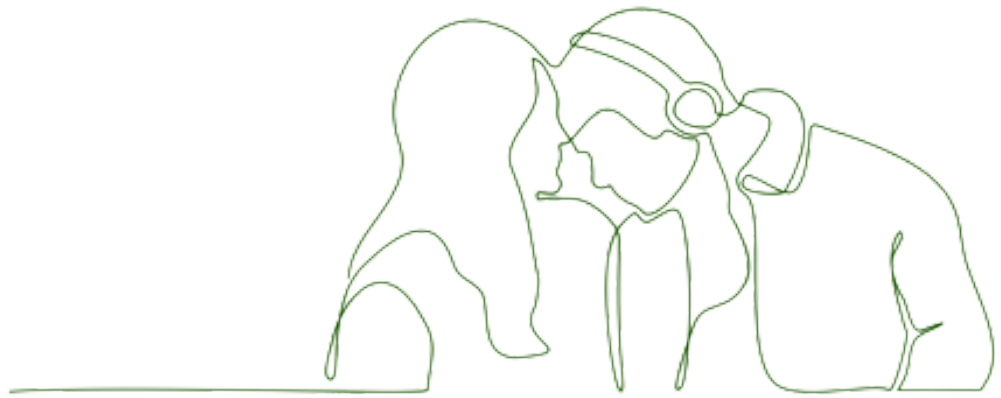




Eight Ways To Strengthen The IACC's Draft Strategic Plan

A dedicated section and budget line for profound autism

Named 45 times in the draft, profound autism has not yet received a dedicated section or funding line.

A standing, public drafting process

Modeled on the national Alzheimer's plan, updated annually through subcommittees that report to the full Committee, in the open.

Citations linked to specific claims

The plan cites 727 sources. Linking each claim to its source would let anyone, families, agencies, or researchers, trace the evidence.

Funding for CMS to match its role

CMS should be resourced to carry out their long list of initiatives

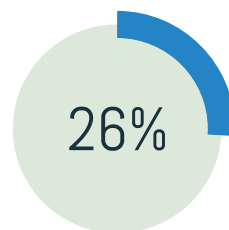
Adopt the Delphi consensus definition of profound autism

A peer-reviewed expert consensus definition already exists (Molecular Autism, June 2026) and includes intellectual disability as a qualifying pathway.

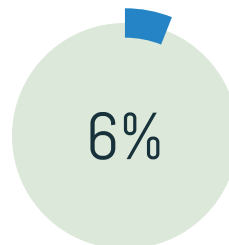
Apply plain-language standards

The draft requires its own Autism.gov portal to meet federal plain-language standards. The plan should meet that same bar and provide opportunity for public comment prior to voting.

According to the CDC:



The percentage of 8-year-old children with profound autism among those with autism is **26.7%**.



According to a 2019 study, **only 6%** of clinical research studies included people with profound autism as participants.

A public workshop before the plan is finalized

NIH used this model for the ALS plan, real two-way input, not just a written comment period.

A model HCBS waiver for profound autism

In some states, families wait 7 to 18 years for home and community-based services. A model waiver template gives states a real starting point.

**Submit your public comment directly to
IACCPublicInquiries@mail.nih.gov before
August 20, 2026 at 5 PM Eastern**